Potential Donor Information

In Indiana, the <u>Postnatal Donation Initiative</u> established that the Indiana State Department of Health would take the lead in promoting awareness concerning a pregnant woman's option to donate postnatal fluid, including umbilical cord blood, as well as postnatal tissue, including the placenta and tissue extracted from the umbilical cord.

Which hospitals in Indiana collect donated postnatal tissue, including cord blood?

- Indiana University Health Ball Memorial Hospital Muncie, IN
- Community Hospital Munster, IN
- Dupont Hospital Fort Wayne, IN
- Franciscan St. Francis Health Indianapolis, IN
- Franciscan St. Francis Health Mooresville, IN
- Indiana University Health Arnett Hospital Lafayette, IN
- Porter Regional Hospital Valparaiso, IN
- Riverview Health Noblesville, IN
- Franciscan St. Anthony Health Crown Point, IN
- Franciscan St. Anthony Health Michigan City, IN
- St. Catherine Hospital East Chicago, IN
- Franciscan St. Elizabeth Health East Lafayette, IN
- St. James Hospital Chicago Heights, Ill
- St. Joseph Regional Medical Center Mishawaka, IN
- St. Joseph Regional Medical Center Plymouth, IN
- St. Mary Medical Center Hobart, IN
- Franciscan St. Margaret Health Dyer, IN
- Franciscan St. Margaret Health Hammond, IN

Which agencies in Indiana currently collect donated postnatal tissue, such as cord blood?

Lifeline Stem Cell

- (Phone) 1-260-749-9105
- (Fax) 1-260-493-0005
- www.lifelinestemcell.org
- For questions or information, email: information@lifelinestemcell.org

What is umbilical cord blood?

Umbilical cord blood or cord blood is the blood that stays in the umbilical cord and placenta after the birth of your baby. This blood contains special cells called <u>stem cells</u> that can help treat diseases in children and adults. The stem cells in cord blood are very simple and undeveloped, and can be transplanted in persons to treat a number of life-threatening diseases.

Stem cells from cord blood are different from embryonic stem cells that come from developing human or animal embryos. Cord blood stem cells do not come from embryos. In the past, cord blood was usually discarded after the infant was delivered. Cord blood can now be collected and stored in a cord blood bank for future use.



Who can benefit from the stem cells in umbilical cord blood?

Cord blood transplants can benefit many people, including immediate and extended family members and non-related children and adults with certain conditions. Cord blood also may be able to help those who are waiting for life-saving treatments. According to the National Marrow Donor Program, transplants of cord blood cells have already saved the lives of thousands of Americans with a variety of diseases. Your baby's umbilical cord can be a lifeline for someone who is very ill.

What medical treatments use umbilical cord blood?

Transplants of cord blood stem cells have been used for many years to treat more than 80 diseases, including conditions such as:

- Leukemia;
- Myelodysplastic Syndromes;
- Lymphoma;
- Anemias:
- Sickle Cell Disease;
- Disorders of blood cell proliferation;
- Inherited disorders of the immune system and other organs;
- Inherited metabolic disorders: and

• Solid tumors not originating in the blood or immune system.

Treatment of these disorders using cord blood is not experimental. Research on emerging therapies in which the patient's own cells are used to repair the body may increase the use of cord blood that is stored for personal use. Scientists are studying whether cord blood can be used to treat other common disorders of the heart, bones, liver, and brain, as well as other conditions including diabetes and Parkinson's Disease.

For a complete list of diseases and conditions in which postnatal donation tissue is standard therapy, is in clinical trials or is experimental, please visit Parent's Guide to Cord Blood Foundation.

How does umbilical cord blood help?

The stem cells in cord blood are important because they make many different types of cells in the body. Stem cells in cord blood can help build new, healthy cells and can be transplanted in people to treat a number of life-threatening conditions. An individual can receive his or her own cord blood for treatment, or more commonly, a person will receive umbilical cord blood donated from someone else.



How is cord blood collected and is it safe?

Collecting cord blood is safe for both babies and mothers. The collection will not affect your baby's health or your birth experience because cord blood is collected after your baby is born. If you would like your baby's cord blood to be collected and stored for future use, you must make arrangements in advance with either a public or private cord blood bank of your choice.

After your baby is born, cord blood is collected from the umbilical cord and placed in a special container that is sent to a cord blood bank. The cord blood and mother's blood samples are then processed and tested. If the mother's blood sample identifies the presence of infectious disease, she will be notified. Once the cord blood bank decides the cord blood can be used, it is stored for future use.

What is the difference between public donation and private storage?

Cord blood is frozen after it is collected and stored in cord blood banks. It is important to remember that not all families are eligible to donate cord blood and not all cord blood collections will meet the requirements for public storage. If you donate your cord blood, publicly or

privately, there is no guarantee that the sample will be a match and will be used in the future. There are two types of cord blood banks: public cord blood banks and private cord blood banks.

Public Cord Blood Banking

Public cord blood banks collect and store donated cord blood stem cells for use with anyone who is in need of a stem cell transplantation. They do not charge donation fees. Public banks do not reserve the umbilical cord blood for the family that donated them. The donations are made available to the general public in order to find the best match. No information about you or your baby is provided to the patient receiving the cord blood. Each year, many adults and children receive life-saving treatment from umbilical cord blood that families have chosen to publicly donate.

Cord blood does not have to be exactly matched to the patient receiving it, but when donated cells closely match the patient, their chances of transplant success improve. Patients are more likely to match someone who shares their racial or ethnic heritage. Cord blood donations are very important to secure transplants for patients who are of minority or mixed heritage, as the need for donations is great but the supply is small.

The American Academy of Pediatrics recommends public donation of umbilical cord blood for all families; however, private banking can be considered only if a *full* sibling has a medical diagnosis for which stem cells are being used for treatment.

Private Cord Blood Banking

A private cord blood bank is a commercial, for-profit organization that advertises directly to parents. If you choose to store your cord blood privately, it will only be available for use by your family and will not be available to public banks for unrelated transplants or research. Private banking allows you to have your baby's cord blood collected and stored for your baby or another close family member if ever needed. Private donation banks usually charge an initial fee for collection and processing and then charge an annual fee for storage. Banking your baby's cord blood in a private bank might provide a match for your baby or siblings. However, there is no guarantee that the cord blood will be a match or will be used in the future.

Choosing either a public or private cord blood bank is a personal decision that you should make for yourself after reviewing information and having a discussion with your health care provider.

What are the costs for ownership and future use of donated cord blood?

If you choose to donate your baby's umbilical cord blood to a public bank where it is made available to others, much like donating blood, it should not cost you any money. Ask your provider if there will be any charge to collect the blood at the hospital.

If you choose to save your baby's cord blood in a private cord blood bank where it will be available only to your baby and family members, the cost could be \$2,000 or higher when your baby is born. A yearly storage fee is also charged. Private banks do not typically charge a fee for the release of the cord blood to your family. There are some family banking programs available for free for those who have a sibling or family member with a condition treated by stem cells, such as Sickle Cell Anemia.



How do families decide if they want to save or donate cord blood?

Families can contact their health care provider to discuss which options are available. In addition, they may contact the resources provided below for more information on public and private cord blood banks.

Where can I get more information about umbilical cord blood banking?

Parent's Guide to Cord Blood Foundation

- Provides information for parents on cord blood banking, and a list of private and public cord blood banks.
- www.ParentsGuideCordBlood.org

The March of Dimes

• www.marchofdimes.com

National Marrow Donor Program

- Provides information about cord blood and a list of hospitals that accept public cord blood donations
- Phone: 1-800-MARROW-2
- www.marrow.org/cord

Health Resources and Services Administration (HRSA)

• http://bloodcell.transplant.hrsa.gov/